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**CHILDREN WITH
SPECIAL HEALTH CARE NEEDS
IN HAMILTON-WENTWORTH**
Analysis of Services Consumed and Needs Identified

Social Planning & Research Council

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of Hamilton-Wentworth

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Analysis of Services Consumed and Needs Identified

Prepared by

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OF HAMILTON-WENTWORTH

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Catherine Flatt

Randi Knight

Pat Senft

Susan West

EXECUTIVE SUMMARY

In June 1994, the Child Care Branch of the Ministry of Community and Social Services requested information on children within the child care system who could be described as being "medically fragile and/or technology dependent". These children are defined as persons who are dependent on technological equipment for life support and/or require frequent or constant professional intervention/supervision.

A working group of the Special Needs Preschoolers Network undertook a study that would not only gather information on the number of children, age 0-12 living in Hamilton-Wentworth who fit this definition but also learn about the needs, both met and unmet, of these children and their families. The working group consisted of representatives from Hamilton-Wentworth Home Care Program, Hamilton Association for Community Living, Early Childhood Program (Chedoke-McMaster), and the Social Planning and Research Council of Hamilton-Wentworth.

The study was also an opportunity to determine the kind of support these children were currently receiving both in and out of the home and who provided the training for medical support for the parents and the others who cared for the children. It was also used as an opportunity for parents to make suggestions about the way in which their children receive support. Hand-delivered questionnaires and in-person interviews were used to gather this information, using the month of February, 1996 as a time frame.

From the 59 surveys that were hand delivered, 21 were returned for analysis. The results of the survey and in-person interviews suggest that although many of the medical needs of the child are being met, there is high demand for greater access to respite, information, formalized training for parents and informal caregivers (family and others), transportation, and alternative models of health service delivery. Parents were found to be the primary deliverers of service and the trainers of others who care for their children.

Needs identified in the study are discussed, with information to support the findings of the study gathered from community and health care providers who work with these children and their families.

Several recommendations are made from this study which include:

- ◆ greater coordination of services and information for parents;
- ◆ creation of a parent support network for families of whose children who are medically fragile/technology dependent
- ◆ development of alternative and additional in-home and out-of-home respite to meet the needs of this population;
- ◆ more support and recognition given to parents through using a family-centred approach in the delivery of services;
- ◆ greater flexibility in Ministry policies to allow for more sensitive and cost-effective service delivery.

Perhaps the greatest recommendation, though, can be illustrated by using the words of one parent who wrote:

"Society and programs need to become aware of the needs of these children medically and otherwise and take all of this into consideration."

It is hoped that this study will increase the awareness and understanding of people in the community of Hamilton-Wentworth of the needs of children who are medically fragile and/or technology dependent and be helpful for those in a position to plan or provide services to this population. It is also hoped that by providing opportunities to discuss the recommendations of this report, resources for these children and their families can be used more effectively through greater collaboration and creativity between service providers, families and funding agencies.

1.0 BACKGROUND

In June of 1994, the Child Care Branch of the Ministry of Community and Social Services contacted Area Offices requesting information on children in the child care system who could be described as being "medically fragile and/or technology dependent". In Hamilton-Wentworth, this request was brought to the attention of the Child Care Advisory Committee, a committee of the Association of Agencies for Treatment and Development (A.A.T.D.) Subsequently, a small group of service providers met with Ministry staff to respond to this request. Through the discussion which took place, it became evident that although some child care programs had limited experience accommodating children with unique health needs, our community lacked a comprehensive understanding of the numbers of children with special health care needs, the range of needs and the scope of issues related to supporting these children and their families.

At the same time, the Integration Resources Hub (see glossary for description) was working towards integrating preschool children with high needs in child care settings. As this effort progressed, children with increasingly challenging health care needs came to the attention of the Hub. The Hub Intake Committee was approached by some families requiring child care whose children had needs never before faced by integrated child care programs in our community. Increasingly, this population was becoming more visible to the child care system. In order to best respond to their needs, a broad spectrum of child care providers, with representation from resource teacher programs, the Regional Municipality of Hamilton-Wentworth, the Ministry of Community and Social Services (Child Care), developmental paediatricians, and the Hamilton-Wentworth Home Care Program came together to explore protocols and procedures relating to the inclusion of these children in the child care system.

As a result of this emerging recognition, a recommendation was made that the Special Needs Preschoolers Network (see glossary) undertake a survey on children with special health care needs in our community. This recommendation was approved and a small working group was formally endorsed to undertake this project. This working group was comprised of representatives from the Hamilton-Wentworth Home Care Program, the Early Childhood Program of Chedoke-McMaster Hospitals and the Hamilton Association for Community Living.

1.1 Population to be Studied

The subjects of the study were children, age birth to 12 years considered, by the Ministry of Health to be “medically fragile/technology dependent”. This includes individuals with medical involvements - those children who are dependent on life-support technology and/or professional intervention/supervision:

- ◆ persons who are dependent on technological equipment for life support (e.g. ventilators, oxygen, total nutrition)

- and/or

- ◆ require frequent or constant professional intervention/supervision (e.g. individuals who require frequent suctioning due to risk of choking or aspiration, gavage (tube) feedings, etc.)

1.2 Anticipated Findings of the Study

By undertaking this study, it was anticipated that the Working Group would:

- ◆ find out the number of children birth to 12 years of age in Hamilton-Wentworth who have unique health needs;

- ◆ learn about the needs, both met and unmet, of these children and their families;

- ◆ determine the kind of support the children currently receive in their home and who provides it;

- ◆ determine which programs the children go to outside their homes, the support given in these programs and who gives it;

- ◆ determine who currently provides training for the individuals providing support;

- ◆ give an opportunity for parents and caregivers to suggest other creative, fiscally responsible strategies to address their children's needs.

2.0 METHODOLOGY

The study was designed over several months of discussion with the working group. Membership on the working group consists of representatives from the Hamilton-Wentworth Home Care Program (Home Care), Hamilton Association for Community Living (HACL), and the Early Childhood Program of Chedoke-McMaster Hospital. Support from the Social Planning and Research Council of Hamilton-Wentworth (SPRC) was secured to assist with the planning and analysis of the information/results.

A hand-delivered questionnaire was selected to survey parents of children who are medically fragile and technology dependent. This method was selected due to its flexibility, low cost, and the ability to ensure confidentiality to the population surveyed. The questionnaire was designed during several meetings of the Working Group.

During these meetings, the expertise of those having worked with children who are technology dependent and medically fragile, enabled the questionnaire to be designed. The questionnaire was divided into three sections. The first section asked for the birth date of the child and the postal code. The next section identified a menu of health/personal care services and requested that parents recall what services they had used during a one month period. By having a menu of services presented, it was hoped that it would increase the reliability of responses. The third section of the questionnaire gave parents the opportunity to identify any unmet needs considered important to themselves, their children and their families.

Parents were asked to complete the questionnaire and detail the services that their child required over a one month period (see questionnaire attached in the appendix). Prior to its distribution, the questionnaire was pre-tested with three families who gave feedback on the questions and format. The option of having a cultural interpreter present, should languages other than English be spoken, was offered to these parents, as was the assistance of the person delivering the questionnaire.

The questionnaire was distributed by and returned to service providers. These service providers were briefed about the project and questionnaire through a letter written by the Working Group. It was felt that this method would not only reduce the costs of postage and handling, but that it would ensure a greater response rate (Babbie, 1989:238). Parents were then also given the option of returning the questionnaire via stamped return envelopes.

A number of in-kind benefits were generously donated to this project. This collaborative investment shows the wide range of interest and concern for this issue. Home Care provided photocopying, secretarial time, and stationery. HACL provided postage and secretarial time to collect and deliver the questionnaires. Members of the Special Needs Preschool Network and the Early Childhood Program assisted with printing and delivery of the questionnaires.

Fifty-nine questionnaires were hand delivered. Twenty-one were mailed back for analysis. To avoid processing duplicate questionnaires and ensuring confidentiality, information was distinguished by the child's birth date and their postal code, found in the first section of the questionnaire. Respondents were not asked to identify themselves by name. However, parents were given a form on which to write their names and addresses, should they wish to receive the results of the study. These forms were separated from the questionnaires.

Information about the use of health supports that a given child required during a certain month, was gathered, calculated and recorded in table form (see Tables 2 and 3). For this study, supports utilized during the month of February, 1996 were reported.

The open-ended questions found in the third section of the questionnaire were analysed by examining the results and identifying common themes. All responses were recorded. This information is presented and discussion of the results are re-enforced with information from available literature, both academic and community-based. Also valuable were comments made by the Working Group and others in the health care system who shared their knowledge of some of the needs and resources available to parents with children with special health needs.

To further clarify the results of the questionnaire, and add depth to this report, additional parent input was sought. All respondents who expressed interest in receiving the results of the study were invited to attend a focus group. However, as response to this forum was low, those who did respond were asked to participate in a one-on-one interview, at their convenience. Three in-person interviews were conducted with parents during June, 1996. These parents were visited in their homes, and information was shared about the preliminary results of the study in which they had participated. Parents shared their comments and concerns about several of the findings through the use of open-ended questions and the semi-structured nature of the interview. The discussions focused on services they relied on to meet their children's needs. These insightful comments are identified in the body of the results section which follows.

3.0 RESULTS

As detailed in a recent report by Homesupport Canada, the most common disabling disorders for children are mental and nervous system disorders, including developmental disability, epilepsy and cerebral palsy (Homesupport, 1995:11). Asthma and physical disabilities are also common (Homesupport, 1995:11). Although the survey respondents were not asked to identify their child's diagnosis, it appears the report's findings concur with Hamilton-Wentworth Home Care Program statistics that show high request for service for those with similar diagnosis to those listed above (Catherine Flatt, Personal Communication, 1996). (It should be noted that the study focused on those children with chronic needs and not on children who have acute needs).

3.1 Questionnaire Section One - Demographic Information

The actual number of questionnaires distributed to children, in both urban and rural areas, who fit with the criteria of a child who is medically and technologically dependent was 59. From these, 21 were returned for analysis. From the questionnaires returned, it appears that these children live throughout the Region of Hamilton-Wentworth (see map of respondents found in the appendix), with some concentration within the City of Hamilton. Only one survey was not identified by postal code.

The age range of children surveyed was from October 11, 1985 - November 2, 1995. With the following breakdown of birth date:

TABLE 1: NUMBER OF CHILDREN IN STUDY BY AGE

Age of Child	0 - 4 Years	5 - 7 Years	8 - 11 Years
Birth Date of Child	1992-1995	1989-1991	1985-1988
Number of Children	13 (65%)	4 (20%)	3 (15%)

n=20

(Note: one respondent indicated only that their child was in school, but did not list the child's birth date)

From the above table, it is noted that the majority of respondents are parents with children under the age of four.

According to Home Care statistics, 59 children were identified. From those, 8% were between 11 and 12, 27% were between eight and eleven, 20% were between seven and five, and 44% were between 0 to four years old. This would indicate that the sample for the survey is fairly representative in age to the total population of children in Hamilton-Wentworth who are considered medically fragile/technology dependent.

3.2 Questionnaire Section Two - Use of Health Supports

The second part of the questionnaire was designed to provide a comprehensive listing of the array of services utilized by the target population. The first question (see attached questionnaire in the appendix) was used to determine which needs were being met in the home and by whom, i.e., the parent, nurse, etc.

All respondents cited that the needs, listed in the Table 2 below were primarily being met by the parent, with training largely being provided by nurse or therapist, both in hospital and at home. This indicates that parents play a significant role in attending to the health needs of their children. Parents were also identified as playing a significant role in training others to provide needs to their children, such as family members and friends. This is confirmed in the literature that "...Parents of technology assisted children are having to assume new roles that require them to learn complicated skills in a very short time...(and that) parents are required to be part-time nurses and sometimes therapists (Homesupport, 1995:7).

The following table details services used and frequency of health/personal care need that is met by whom, and who is providing training inside the home (Table 2). Please refer to the legend for abbreviations.

TABLE 2: Frequency of Health/Personal Care Need Met In-Home by Parent/Nurse**Legend**

n/a	- Not Applicable
Home Care	- Hamilton-Wentworth Home Care Program (Ministry of Health)
MUMC	- Chedoke/McMaster University Medical Centre
SSAH	- Special Services At Home (Ministry of Community and Social Services)
Sick Kids	- Hospital for Sick Children, Toronto

Need/Medical Support	Number of Children Who Have this Need Met in Home by Parent	Number of Children Who Also Have Services Provided by Person Other Than Parent	Training for This Support Provided By
Tracheostomy	1	1 priv. nurse	nurse or therapist in hospital
Suctioning -Deep	1	1 priv. nurse	nurse or therapist in hospital
Suctioning -Shallow	3	2 nurse or therapist-Home Care 1 priv. nurse	parent/nurse or therapist - Home Care nurse or therapist in hospital
Postural Drainage	2	0	nurse or therapist - Home Care
Chest Physio (Care)	6	3 nurse or therapist-Home Care 1 priv. nurse	nurse or therapist in hospital nurse or therapist - Home Care parent physician
Oxygen	5	2 nurse or therapist-Home Care 1 priv. nurse 1 SSAH	parent oxygen supply company nurse or therapist - Home Care
Tube Feed - G Tube	5	1 SSAH 2 nurse or therapist-Home Care 1 priv. nurse	nurse or therapist - Home Care physician therapist in hospital parent

Need/Medical Support	Number of Children Who Have this Need Met in Home by Parent	Number of Children Who Also Have Services Provided by Person Other Than Parent	Training for This Support Provided By
Tube Feed - J Tube	3	1 SSAH 2 nurse or therapist-Home Care 1 family member	physician therapist in hospital
Tube Feed - Nasal Gastric - In Situ	1	0	nurse or therapist in hospital
Tube Feed - Nasal Gastric-Inserted Each Feed	n/a	n/a	n/a
Ostomy Care	3	SSAH 1 nurse or therapist-Home Care	parent therapist in hospital physician
Catheterization - clean	5	1 nurse or therapist-Home Care 1 self	physician nurse or therapist in hospital Easter Seals Super Bears Camp
Catheterization - sterile	2	1 priv nurse	nurse or therapist in hospital nurse or therapist - Home Care
Ventilation	0	0	0
Central Line -Hyper alimentation	1	1 SSAH 1 nurse or therapist-Home Care	physician nurse or therapist in hospital
Central Line - Chemotherapy	0	0	0
Dialysis	0	0	0
Seizure Activity	2	0	parent physician nurse or therapist - Home Care
Seizure Activity - needing immediate administration of medication (e.g. Valium rectally)	5	4 nurse or therapist-Home Care	parent nurse or therapist in hospital physician nurse or therapist - Home Care

Need/Medical Support	Number of Children Who Have this Need Met in Home by Parent	Number of Children Who Also Have Services Provided by Person Other Than Parent	Training for This Support Provided By
Seizure Activity - needing immediate transfer to hospital	3	1 SSAH 1 nurse or therapist-Home Care	physician nurse or therapist - Home Care
CPR Readily Available (e.g. high risk)	4	1 SSAH 1 nurse or therapist-Home Care 1 priv. nurse	nurse or therapist in hospital St. John's Ambulance physician nurse or therapist - Home Care
Medication - Orally	13	3 SSAH 3 nurse or therapist-Home Care 1 teacher 1 other family member 1 priv. nurse	parent physician nurse or therapist in hospital nurse or therapist - Home Care
Medication - Rectally	5	1 other family member 1 nurse or therapist-Home Care	nurse or therapist in hospital parent physician nurse or therapist - Home Care
Medication - G Tube	6	4 nurse or therapist-Home Care 1 SSAH	physician nurse or therapist in hospital parent nurse or therapist - Home Care
Medication - J Tube	1	1 nurse or therapist-Home Care	parent

Need/Medical Support	Number of Children Who Have this Need Met in Home by Parent	Number of Children Who Also Have Services Provided by Person Other Than Parent	Training for This Support Provided By
Medication - Aerosol	7	2 SSAH 4 nurse or therapist-Home Care 1 priv. nurse 1 other family member	physician nurse or therapist in hospital parent nurse or therapist - Home Care
Continuous Professional Input	6	1 physician 4 nurses or therapists - Home Care 1 priv.OT 1 SSAH 1 visiting nurse	nurse or therapist in hospital physician
Immuno Compromised	1 (transplant)	0	0
Other - (see rows below, self-identified)			
Development	1	SSAH	parent
Cardio-Respiratory Monitor	1	parent	not recorded

n=21

From the above data in Table 2, it becomes clear that a wide variety of services and caregivers were involved in administering to the needs of these children. Teams of parents, nurses, therapists, and Special Service at Home workers (SSAH) were responsible for delivering services. From the large number of services cited, it would follow that service delivery would require complex coordination of care.

Another finding from the above data is that after parents, the majority of the training for services provided in the home was from nurses and therapists with the Home Care Program. It was also frequently noted that training was provided in hospitals, by nurses, therapists and physicians.

The third table, Table 3, details the needs and services provided to children (who are technologically dependent) outside of the home. (Please refer to the legend in Table 2 for abbreviations).

TABLE 3: Needs/Support Identified and Met Out-of-the-Home
(Frequency of Need, Location, and Provider and Trainer Identified)

Need/Medical Support	Number of Children With This Need/Support	Location of Provision of Support	Support Provided By	Support Training Provided By
Tracheostomy	n/a	n/a	n/a	n/a
Suctioning -Deep	1	MUMC	nurse on site	
Suctioning -Shallow	1	MUMC	not recorded	not recorded
Postural Drainage	1	MUMC	staff	not recorded
Chest Physio	3	school MUMC	Home Care staff	not recorded
Oxygen	3	school MUMC alternate care	teacher parents SSAH Home Care staff on-site	parent nurse in hospital Home Care staff
Tube Feed - G Tube	2	school camp St. Joe's respite preschool	staff on site nurse on site teacher	parent
Tube Feed - J Tube	2	preschool alternate care	staff on site	parent Home Care
Tube Feed - Nasal Gastric - In Situ		MUMC	staff on site	n/a
Tube Feed - Nasal Gastric-Inserted Each Feed	n/a	n/a	n/a	n/a
Tube Feed - Nasal Gastric - Gag Reflex Present	1	preschool	teacher	parent
Ostomy Care	1	alternate care	not recorded	physician
Catheterization - clean	4	school camp	staff on site teacher parent VON nurse	Home Care parent
Catheterization - sterile	1	school	teacher	Home Care
Ventilation	n/a	n/a	n/a	n/a
Central Line -Hyper alimentation	n/a	n/a	n/a	n/a

Need/Medical Support	Number of Children With This Need/Support	Location of Provision of Support	Support Provided By	Support Training Provided By
Central Line - Chemotherapy	n/a	n/a	n/a	n/a
Dialysis	n/a	n/a	n/a	n/a
Seizure Activity	2	school respite MUMC	staff staff	parent
Medication - Orally	2	school	teacher staff	not recorded
Medication - rectally	n/a	n/a	n/a	n/a
Medication - G Tube	2	alternate care MUMC	parent SSAH Home Care	parent nurse in hospital staff
Medication - Aerosol	2	school	teacher	parent
Continuous Professional Input	3	school recreation program Sick Kids	Home Care nurse weekly	
Immuno Compromised	n/a	n/a	n/a	n/a
Other (see rows below, self-identified)	-	-	-	-
Swimming	1	rec. program camp	volunteer	not recorded
Speech Therapy	1	preschool St. Joseph's Respite	not recorded	not recorded

n=21

The most common medical needs identified in Table 3 are oxygen and the oral, or rectal administration of medication. (In this reference to medication, professional judgement is required as to whether to administer medication or transport the child to the hospital). Not only did these needs seem to be in the greatest need in terms of services, but they also involved the greatest variety of individuals in the provision of these services and in the training for administering the service.

As detailed in the comparison between Table 2 and Table 3, the amount of services delivered to children outside of the home is significantly less than those provided in the home. And, as the role of the parent diminishes in services provided outside the home, the role of the school, hospital and respite programs increase within this sphere of services. However, even outside the home, it appears that the parent often plays a role in the training of staff, especially non-health professional staff, such as teachers and child care staff.

It is also interesting to note that parents specified non-medical needs outside of the home, such as swimming and speech therapy when asked to identify other needs. These services may often be overlooked, but they were reported as important for these children. This will be discussed further in the analysis.

3.3 Questionnaire Section Three - Analysis of Comments made about Met and Unmet Needs

In the third part of the survey, respondents were asked three open-ended questions. The first question was asked in two parts. The first part of the question asked, "are the services that your child is receiving meeting his/her needs at home and the needs of the family?"

TABLE 4: Percentage of Respondents Who Considered Their Needs Met/Unmet

Are Needs Being Met?	Needs are Being Met	Needs Somewhat Being Met	Needs are not Being Met
% of respondents	52% (n=11)	43% (n=9)	5% (n=1)

n=21

A slight majority of respondents (52%) claimed that their children were having their needs met at home. 43% of respondents indicated that their children's needs (in-home) were somewhat being met. Only one respondent indicated that their child's needs were not being met in the home.

The second part of this question asked respondents, "If the needs of your child and family are not being met, please provide examples of the unmet needs, and tell us why they are not being met". Respondents generally related to needs, other than health, in their responses. This may be explained by one parent who views her child's disability in a relative manner and who in response to this question stated "...our needs are not health related. Our son has C.P and is healthy. He just needs someone to help be his body..." Other responses included the following unmet needs: more time to provide care for the rest of the family, access to child care, training for parents and other informal caregivers, supports at school, having to take unnecessary services instead of services considered to be more valuable.

The next question, question two, asked respondents for their suggestions on how these needs could be better met. Solutions suggested included:

- more in-home support
- greater access to respite care
- education
- transportation
- assistance with technical devices
- and social interaction opportunities for their medically fragile/technology dependent children
- alternatives to costly services, through training for parents and involvement of extended family in the same training
- flexible coordination of services
- use of extended families
- and emergency respite vs. hospital care

(A complete list of responses to this question is found in the appendix)

The third open-ended question asked, "Are there programs outside your home that you would like your child to go to, but your child is unable to go there because of medical needs? Please name the program and the needs your child would have while there". In response to this question, there appeared to be several unmet needs for the children both in terms of medical and social supports. These included requests for information, daycare, respite, staff training and attention in the detail of care provided.

To further clarify these issues, in-person interviews were conducted with parents. Additional information was also sought from the existing literature. The discussion which follows which details the issues raised during the course of the study.

Time

More time was frequently cited as a need by the majority of respondents. These comments included having more time in general, but more specifically, having greater access to respite time in order to take care of other children, do errands about town, socialize, and work, both in and outside the home.

Access to Respite

Respite is reported to reduce the burden of families raising a child with developmental disabilities at home by: relieving familial stress, improving family functioning, improving parental attitudes towards the child and reducing social isolation (Botuck and Winsberg in Home care, 1995:11).

As previously stated, respite, both in and outside the home, was identified as a high need for respondents. Many saw this as a solution to reducing family stress and providing a low-cost alternative to hospital care. According to recent research in respite services, those families who use respite services reported "...increased satisfaction with life; more hope for the future; improved attitudes toward their child with a disability; and increased ability to cope..." (Folden, S.L et al, 1993:103).

Out-of-Home Respite Care

As detailed in the booklet A Starting Point - A Guide to Services for Parents of Children with a Disability - 2nd Edition, there are several options available to parents and their child within Hamilton-Wentworth for respite outside the home. These include:

- ◆ Charlton Family Support Program (HACL) - Offers weekend and summer respite for individuals with developmental disabilities, under age 21
- ◆ Extend-A-Family - offers volunteer host families who will care for an individual with disabilities once a month
- ◆ Alternate Care Program - offered through Children's Aid Society (CAS) and Catholic Children's Aid Society (CCAS). They provide alternate homes in the community whose parents have requested this form of support for their children up to 10 days a month.
- ◆ St. Joseph's Hospital - planned respite only, emergency respite in hospital setting

Although it appears that there are a number of options for respite care, from the long waiting lists cited by all of these agencies, the amount of respite care available does not meet the current demand for service.

There are also a few other respite programs in neighbouring communities, such as Halton and Brant. However, as many respondents cited transportation difficulties, it is unlikely that preference would dictate consuming services outside the region. However, one sub-committee member confirmed that parents will use services as far away as Toronto to access respite. The choice for going outside of Hamilton-Wentworth may be associated with long waiting lists for respite care, as one respondent indicated. This may also indicate that these services and programs are not able to meet the high demand. For instance, according to HACL, "...we can have 8 children in care on a weekend and another 18 on the waiting list..." (Personal Communication, 1996).

In-Home Respite

There are also several options for short-term in-home respite support. These include both programs that parents have to pay for and those that are subsidized. These are listed below:

- ◆ Special Services at Home Program (SSAH)
- ◆ Sitter/Companion Programs - Hamilton Association for Community Living, Extend-A-Family
- ◆ Ontario Ministry of Health's Home Care Program

Although these are available options, there are limitations when accessing in-home respite, for example, not all families who apply for SSAH receive funding.

Sitter companion programs may not have sitters with the necessary skills to care for children with special needs.

Home Care services are limited in the number of hours available.

Some families may wish to purchase additional skilled services, for example, a private nurse. However, this is very costly at \$20 to \$30 per hour and may only be available to those with higher incomes or private insurance.

Respondents further noted that respite care is not well coordinated in Hamilton-Wentworth and more energy should be put into this task as demand continues to grow (in-person interview, 1996).

According to many professionals who work with this population of children, respite has positive impact on both the caregiver and the child (Flat, Din., Senft, Personal Communication, 1996) especially in reducing isolation and loneliness. These have been cited in the literature as two resulting issues for mothers with children who have special health care needs (Homesupport, 1995: literature review). This was also confirmed by the study when several respondents indicated that they had very little time for a social life. One respondent stated, "...there is an expectation that if you have a sick kid then you should be a saint, and never go out...". This may be addressed by the use of alternative models of respite care.

Models of Respite Care

Models of respite for families with medically fragile ITD children do exist and may be used as an effective alternative for service provision to families with children who are medically fragile/technology dependent.

One alternative is to closely examine the use of informal caregivers and perhaps take greater steps to formalize their involvement. This may be accomplished by involving family members and friends in the same training that parents receive while in hospital. This would build on a resource already considered to be valuable to many parents who have children who are medically fragile/technology dependent. During the study, several respondents also indicated how much they rely on family and friends for respite, especially in-home. One parent claimed that she was more comfortable using someone she knew than using a Home Care worker.

There are also out-of-home respite models for this population that may be examined as alternatives to hospital care. In London, a respite care centre was designed that provides planned and emergency respite to children at the "Kids Country Club" on Fridays, Saturdays and Sundays. According to Pam Alambets, Case Management Supervisor, London-Middlesex Home Care) this facility is funded by the Long-term Care Office and accommodates 3-4 children each weekend (personal communication, 1996). This program is in its second year of operation and is seeking additional funding to increase the hours of operation. This initiative is the result of a group of dedicated parents.

Another initiative is the Safehaven Program, a parent run, community-based, not-for-profit agency. According to Beverley Gordon, Executive Director, this agency provides respite care and has been brought about by parents and volunteers. The organization was incorporated in 1986, and since that time it has established three homes in the Toronto area. The homes are located to offer parents respite that is no more than ten minutes away from their children. Safehaven receives funding from the Ministry of Community and Social Services (MCSS) and private donations to care for 18 children at a time (6 children in 3 homes).

There are currently 48 families who are actively involved in the Safehaven program. Parents primarily use the service for weekend respite. Safehaven will take children on a crisis basis and will also care for the able-bodied children of parents needing respite. Staff will pick-up and deliver children and encourage parents to network with one another. Parents are charged \$25 per day, but no one is turned away if they can not afford to pay.

Similar initiatives that could be implemented in Hamilton-Wentworth. This would involve bringing service providers and parents together to plan and provide a more collaborative use of services, especially in the area of emergency respite.

Transportation

During the study, access to transportation was often identified as an issue. Although DARTS, (Disabled and Aged Regional Transit System), provides services, there are several barriers identified for children who are medically fragile and technology dependent. This service only provides transportation within the Region of Hamilton-Wentworth, making it complicated for those who have to travel outside the region to use the services in Toronto e.g., Hospital for Sick Children. Also, children have to be over 18 months of age before being allowed to take DARTS. According to their Community Relations Coordinator, DARTS is not equipped to carry children in car seats, only wheelchairs (Personal Communication, 1996). However, children who do qualify for DARTS may be able to access taxi service, through a local taxi company. This service is contracted to provide rides, as an alternative to DARTS. However, taxis are more costly and still legally require parents to supply their own car seats. Registration and booking in advance also may be problematic for those needing emergency trips. However, it appears from the responses that it was the "hassle involved with getting around" that was the greatest barrier and not so much the cost of transportation.

But, according to one parent, the issue of cost did play greatly in accessing transportation.

"I am on Social Assistance. 22% of my cheque was just cut-off. I've had to sell my car. I can't go out and take a job because I have to look after "S". I use taxis for transportation. But taxis don't have car seats. I don't get subsidy for taxis and I can't use DARTS until "S" is 18 months old."

Financial Costs for Services

According to [A Starting Point](#), there are several alternatives to assist in covering the cost of services for children with disabilities. These include the Assistive Devices Program, Handicapped Children's Benefit, the Regional Municipality of Hamilton-Wentworth, Income Tax Credits, Vehicle Sales Tax Rebate, The Easter Seal Society, Ministry of Health Dental Assistance Program, Hamilton-Wentworth Home Care Program and private insurance programs. Many of these programs offer assistance around children's medical needs. But even with these supports, many of which are geared to income, parents are still limited in what services they can access.

Caring for a child who is medically fragile/technology dependent places a large financial burden on families. Parents may have difficulties working outside the home. Often the extent of care required will make a parent often feel compelled to remain in the home to care for their child. In other situations, child care may not be available which could accommodate the child's medical needs. One respondent expressed the desire to work, but was held back by the need for attention of her child's seizures.

Another factor related to the issue of cost for services was identified by one respondent who stated that "to get the services that we need, we must accept unnecessary services..."(parent of 7 year old child). This may be addressed through further coordination of services. It also may be addressed by a move towards more family-centred care, in which the family is more involved in the planning and choice of the care of the medically fragile/technology dependent child.

One parent made an interesting point about having access to emergency respite as an alternative to costly hospital care. "If something happens to me, they will have to admit us both into hospital. This will cost Home Care and the health system a great deal of money...". Again, this raises the issue about access to respite as an alternative to reduce costs to the health care system.

Access to Information/Training

Access to education and information was identified as an unmet need several times, both in the questionnaires and in the in-person interviews. At present, there are several sources available to assist parents when navigating the maze of services. A resource publication called "A Starting Point" is available to parents. Also, a libraries of information, or "family resource centres" are available at Chedoke and McMaster Hospital sites and was established by parents and staff. These "family resource centres" provide access to computers with updated information about services and reading material about health care, etc. But the challenge remains to ensure that all parents have equitable access to this information (Knight, Personal Communication, 1996). According to one parent, when asked about access to information as an issue, "I found that sometimes I was getting information after the fact. I have just taken a tube feeding workshop. If I would have had this before, I could have used it as soon as I got home. It would have given me something to do while I was waiting around in hospital."

According to the Working Group, there are a number of points of community access to find information for this population. For example, Home Care Case Managers and Easter Seal Staff are often used as a resource as they are well informed about programs and services and often provide links to services. According to the study findings, The Starting Point document was identified as helpful, but with any printed information, it is crucial that it be regularly updated. Updating on a regular basis would be helpful as would having access to internet sites through the family resource centres. Parents could then have access to an alternative source of information about their child's health care.

Several other suggestions were made to address this issue. One suggestion was made to have information "...ready to help people know what other services are available and where to go for the help you cannot provide (yourself)..." Another parent suggested the use of a buddy system, which would match parents with older children who have experienced similar difficulties facing new parents (in-person interview, 1996).

Access to Outside Programs and the Details of Care Offered

Several respondents indicated a need for programs/supports outside the home. These needs ranged from preschool (daycare) placements to more educational assistants being available in school settings. However, training and attention to detail of care were noted as two problems faced in accessing services outside of the home. Once waiting lists (also identified as an issue) had been overcome, it appeared that staff were "too busy to accommodate to their children's needs". This may reflect the class size or ratios of care giver to children. One respondent noted that additional training, specifically CPR, should be made available to staff.

To give some perspective to this issue, one respondent, clearly made the case for needing constant, educated care:

"I would like her in daycare so I could work, but (her) seizures can be very subtle. Last week she had about 20 atonic seizures, followed by non-convulsive status epileptics. If you didn't know what to look for, you might think she just wasn't feeling well, but it was a life threatening emergency." (mother of 2 year old with special needs)

Another respondent stated her concerns about attention to detail of care when her child was in school:

"Her lunch is one hour long. During this time her food is to be warmed, set out and she has to be toiletted. Actual eating time is about 45 minutes. This is not enough time to get the proper amount of food and drink required...she is at risk of aspiration...the teacher put in a request to the Board to get an hour and a half for my daughter's lunch. They refused."

Need for Interaction with Other Children

The need for time for children with special health needs to socialize with other children was identified as an issue. When asked to further clarify this point, one parent of a one year old, stated the importance her other children played in helping with her special needs child's development.

“(He) was number four, so we were lucky in that he has other kids to interact with. They are great for stimulation. Other kids show him toys and give him attention while I’m busy.”

But the situation is more grave for those with only one child. Here interaction is limited. And, as one parent reported, the stigma of having a “sick” child will often prevent other parents from letting their children play with children who have visible disabilities. One parent who was interviewed stated that “...some parents are too embarrassed to take their children to the park, because of how people stare and pity the child and family...” (in-person interview, 1996).

There are many difficulties that arise when parents decide to place their children in child care settings. These include lack of resources to train staff, lack of nursing support, and complications arising from exposure to illness. As previously noted, this population of children require constant attention and require staff to have training to use technical devices. Judgements regarding administering of medication or hospitals may be required by a medical professional. Many child care settings do not have access to resources, training and support staff to be able to meet the needs of these children.

Professional nursing support from Home Care is not available in child care settings. (Home Care can, however, provide nursing support within publicly funded schools). Also, children considered to be medically fragile may be at greater risk of contracting illnesses than other children. One mother indicated that her child “...would likely spend more time out of daycare than in daycare because she would pick up things so easily...”.

Impact on Other Family Members

The impact of having a medically fragile/technology dependent child on other family members can be great.

During the in-person interviews, one parent indicated that:

"Our healthy 4 year old son had a hard time. When I was at Sick Kids, I wasn't there for him. The other kids never had a proper routine, they didn't know where they would be having dinner or where they would be sleeping. My son asked me, "Is "(my brother)" ever going to get better?" My healthy son was very emotional. He would start crying over anything. When the hospital stay ended, though, he was fine. Everything was just always so topsy turvey - so much change for them."

According to the literature, "...distress is 2 to 3 times more prevalent in mothers of children with disabilities, than in mothers of non-disabled children..."(Miller, et al, 1992: 587). However, other family members' role in supporting the parent and the child with special needs can not be understated.

One mother of a school aged child with special needs wrote:

"At times of need like surgeries I am very lucky to have close friends and family to help with my other daughter she is older now and more understanding but the other day she told me she wished she was in a wheel chair so she would get all the attention, almost killed me. It was then I became aware of just how lonely she gets at times. It effects the WHOLE family."

The literature indicates that more children's health and developmental services are moving towards a model known as family-centred care, which recognizes parents as experts and the professional as providing support and guidance (Homesupport, 1995:40). This model values all members of the family being involved in the care of child through effective communication and collaboration in all aspects of planning and delivery (CACC, 1996:9).

CONCLUSION

Society and programs need to become aware of the needs of these children medically and otherwise and take all of this into consideration (mother of child with special needs).

The focus of the study has been children whose age ranges from birth to twelve years old, their parents' perceptions of met and unmet needs, and the services the children use. It is important to note that as these children move from childhood through adolescence and into adulthood, they will have continuing medical needs that must be met to ensure quality of life.

It is hoped that this study will increase the awareness and understanding of people in the community of Hamilton-Wentworth of the needs for children who are medically fragile/technology dependent and be helpful for those in a position to plan or provide services to this population. We further hope that by providing opportunities to discuss the recommendations from this report, we may begin to determine ways in which we can better use the resources we have, through greater collaboration and creativity. It is our belief that changes to the health care system that involves parents, with the support of service providers, will yield the most creative results.

The Working Group

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RECOMMENDATIONS

From the results of the questionnaire and in-person interviews with parents, the following recommendations are made to encourage:

- ◆ greater coordination of services and information for parents;
- ◆ creation of a parent support network for those with children who are medically fragile/technology dependent ;
- ◆ development of alternative and additional in-home and out-of-home respite to meet the needs of this population;
- ◆ more support and recognition given to parents through using a family centred approach in the delivery of services;
- ◆ greater flexibility in Ministry policies to allow for more sensitive and cost-effective service delivery.

Although it is recognized that this is a time of fiscal restraint and budget cutting in the health care system, many of the above recommendations may be accomplished using existing resources within our community.

GLOSSARY OF TERMS/ABBREVIATIONS

Alternate Care Programs	Offered through the Children's Aid Society and Catholic Children's Aid Society. Programs will assist the family of a child with a developmental disability to connect with a family in the community who will share in the care of the child. Children stay with the Alternate Care family a few days each month.
CRDP	Children's Rehabilitation and Development Program
Home Care	Hamilton-Wentworth Home Care Program
Integration Resources Hub	An affiliation of agencies/services in the Hamilton-Wentworth community, which shares in planning , developing and deploying their resources so that preschool children with special needs receive flexible support in the child care setting of their family's choice.)
MUMC	McMaster/Chedoke University Medical Centre
SPRC	The Social Planning and Research Council of Hamilton Wentworth (SPRC) is a non-profit agency funded by the United Way, the Regional Municipality of Hamilton-Wentworth and private donations. The SPRC assists groups to carry out their own research projects including help with drafting surveys through to comprehensive needs assessments and program evaluation.
Special Needs Preschoolers Network	The Special Needs Preschoolers Network is a consortium of agencies and organizations dealing with children with special needs that advocates for the development and delivery of effective early intervention services and strives to enhance the quality of service for children, youth and their parents and the individuals who work with them.

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APPENDIX

Open-Ended Questions

Question 2: Do you have suggestions how to meet these needs?

Responses included:

- ◆ respite to care for other children (x4)
- ◆ education around catheterization and self-care for children over ten
- ◆ in-home care program
- ◆ summer camp relief
- ◆ flexible, individually created
- ◆ assistance in home with outings to the community
- ◆ respite to spend time with other children
- ◆ enrolling other children in programs or activities to give them attention outside of the home
- ◆ respite for housework, socializing, errands
- ◆ special feeding chair
- ◆ stroller with high back to support
- ◆ greater access to Charlton House
- ◆ workshops, training
- ◆ safe pre-school or nursery programs
- ◆ assurance of private insurance coverage of in-home support
- ◆ greater number of hours through home care
- ◆ access to other children
- ◆ transportation issues (3x)
- ◆ having extended family help out
- ◆ costs involved with time and money

Question 3: Are there programs outside your home that you would like your child to go to, but your child is unable to go there because of medical needs? Please name the program and the needs your child would have while there.

Responses included:

- ◆ too busy to accommodate to child's needs
- ◆ area of room too small for him to play on the floor
- ◆ not safe enough environment to leave him on his own
- ◆ need for daycare (x4)
- ◆ reduce waiting lists
- ◆ knowledge of CPR for sitters (training)

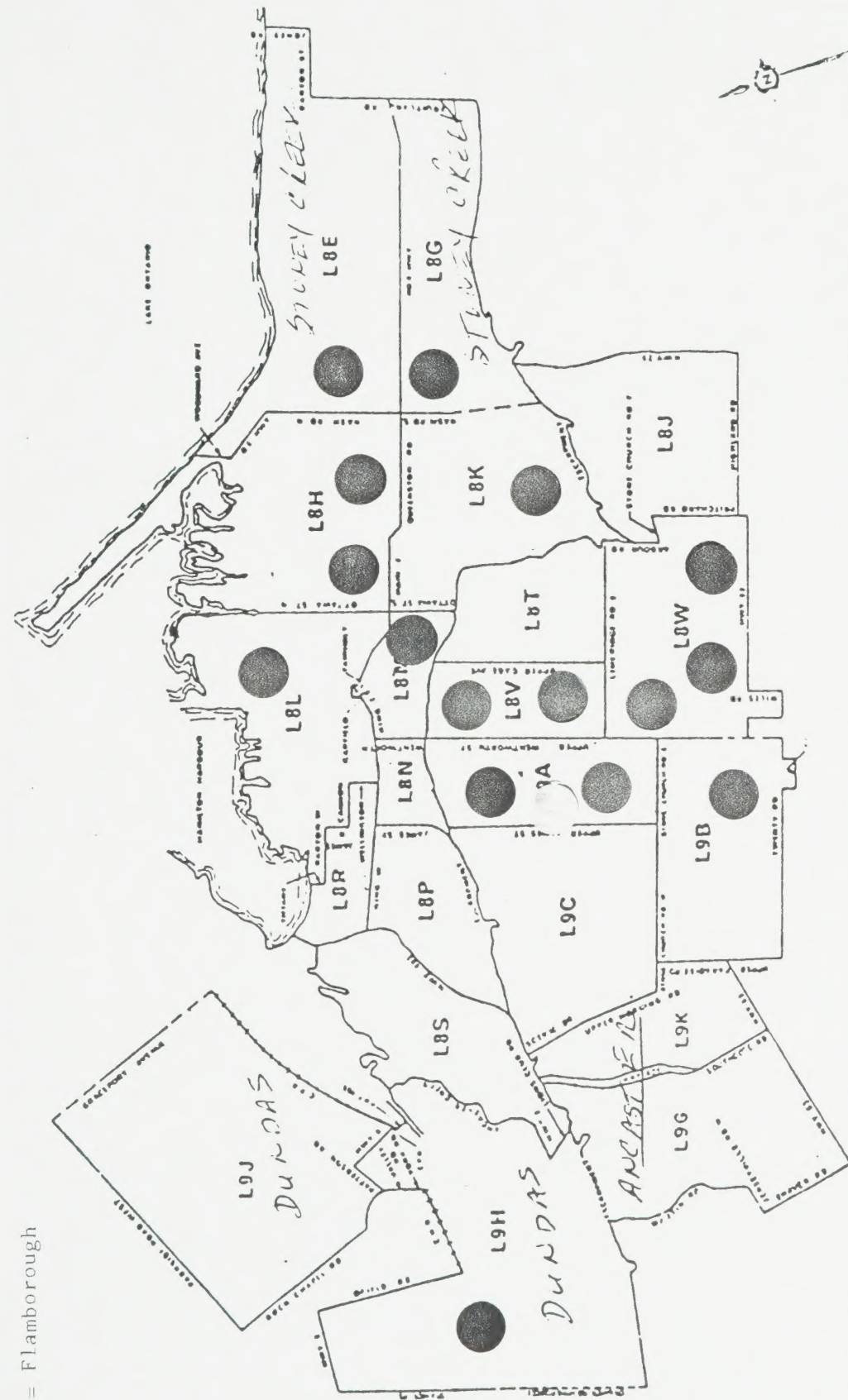
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